## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>SNAPSHOT OF THE PHRN</td>
<td>3</td>
</tr>
<tr>
<td>CHAIRMAN’S MESSAGE</td>
<td>4</td>
</tr>
<tr>
<td>REPORT FROM THE PHRN CHIEF EXECUTIVE</td>
<td>6</td>
</tr>
<tr>
<td>CREATING A SUSTAINABLE FUTURE</td>
<td>8</td>
</tr>
<tr>
<td>PHRN GOVERNANCE: ENHANCEMENT AND PROGRESSION</td>
<td>10</td>
</tr>
<tr>
<td>DATA LINKAGE CAPABILITIES AND OPERATIONS: EXPANSION AND TESTING</td>
<td>13</td>
</tr>
<tr>
<td>NATIONAL STRATEGIES AND INTERNATIONAL COLLABORATIONS</td>
<td>19</td>
</tr>
<tr>
<td>FINANCIAL YEAR IN BRIEF</td>
<td>29</td>
</tr>
</tbody>
</table>

Produced by the Population Health Research Network Program Office

Address: 105 Hay Street  
Subiaco Western Australia 6008  
Phone: (08) 6389 7300  
Email: phrn@ichr.uwa.edu.au

The Population Health Research Network is an initiative of the Australian Government conducted as part of the National Collaborative Research Infrastructure Strategy.
SNAPSHOT OF THE PHRN

- Established in 2009 to develop national health data linkage infrastructure
- Has received $33m of Commonwealth funding and $42m of cash and in-kind support from state/territory governments and academic partners
- A distributed network of Project Participants providing infrastructure and client services to researchers from all over Australia
- 6 regional data linkage units located in QLD, NSW/ACT, VIC, TAS, SA/NT and WA
- 2 national data linkage units located at the AIHW in Canberra and at Curtin University in WA
- A remote-access secure laboratory for the storage and analysis of linked data based at the Sax Institute in NSW
- A national coordination office based at the Telethon Institute for Child Health Research in WA

PHRN VISION

A valued national resource generated from linkage of population data from a broad range of areas such as health, education and community services and used for research to inform policy, planning and management to improve the health and wellbeing of all Australians.

PHRN MISSION

To build a national data linkage infrastructure by working collaboratively with key stakeholders including data custodians, researchers and the community. This will support research of national relevance which results in improved policy making and service delivery and demonstrates global best practice in maximising the benefits to the Australian community whilst preserving individual privacy.

For further information please visit www.phrn.org.au.
CHAIRMAN’S MESSAGE

In 2012-13, PHRN completed its fourth year of operation and its second year with EIF-SSI funding for further development of Australia’s national health data linkage/integration infrastructure.

The PHRN Management Council provided oversight on the implementation of the investment plans governing its programs of funding. Scheduled quarterly meetings in capital cities across Australia to consider and make decisions on key PHRN issues continued in 2012-13 with a continued focus on strategic planning and building on the return on Commonwealth and co-funder investments. Commitment by the PHRN Project Participants saw an additional 40 million records being linked into master linkage files in the regional linkage units, continued expansion of the expertise, knowledge and technical understanding in the data linkage community; completion of linkage of data from four states for the first Proof of Concept Collaboration representing over 45 million records; and the official launch of the PHRN’s unique Secure Unified Research Environment (SURE) facility for highly secure data access and analysis. A steady increase in the number of project applications submitted to the jurisdictional and national data linkage units over the year reflects the advancing maturity of the PHRN infrastructure and recognition by the research community of the value in utilising these resources to undertake nationally and internationally relevant research.

A key focus of the Council continues to be the future sustainability of the PHRN. During the year, Council had the opportunity to provide submissions to a number of bodies tasked with strategic review and planning of national research and infrastructure investment and policy surrounding use of publicly held data. In August 2012 Council submitted a response to a consultation paper commissioned by the Federal Government’s Australian Research Committee (ARCom) which sought to identify critical areas in which research capacity is essential in order to develop a National Research Investment Plan. The Investment Plan sought to provide a whole-of-government framework against which future major strategic research funding decisions could be taken. The Council’s submission accordingly highlighted the immense value of data linkage infrastructure to support the conduct of high quality population-level research in areas of national significance and provided a strong argument for future investment in the PHRN. Council also provided submissions to the McKeon Strategic Review of Health and Medical Research and The Big Data Strategy Issues Paper issued by the Australian Government Information Management Office.

In August 2012 DICCSRTE announced that it had successfully negotiated access to $60m of funding through redirection of several existing research block grants. Known as the Collaborative Research Infrastructure Scheme (CRIS), the goal of this funding was to keep operational until at least December 2014 key components of national collaborative research infrastructure facilities originally funded under NCRIS and/or the Super Science Initiative. A competitive selection process was held during October and November 2012 and the PHRN was successful in securing $3.085 million through the CRIS. PHRN CRIS funds have been allocated to the national elements of the network comprising of national coordination including governance and management activities and contract and financial management (PHRN Program Office); national data linkage services (CDL and AIHW); and secure data access (Sax Institute’s SURE facility). This investment will ensure the continued operation of these elements through to the end of 2014 and I would like to sincerely congratulate and thank the Council and all Project Participants for their contribution to this process which was undertaken in an extremely tight timeframe.
In conjunction with the announcement of the CRIS funding, PHRN Chief Executive Dr Merran Smith and I had the opportunity to meet with Senator Chris Evans, Federal Minister for Tertiary Education, Skills, Science and Research in Perth in October 2012. The Senator was across the work of the PHRN and was aware that the PHRN was applying for further funds and requires long-term infrastructure support. He emphasised the importance for the Government to see a link between research using linked data and evidence-based policy change. Senator Evans felt that the outcomes of the Proof of Concept Collaborations and the contributions these projects make to health policy would be more important than technical achievements in future funding considerations. Emphasis on progression of the four Proof of Concept Collaborations was determined to be a network priority by the Council in its strategic planning activities and based on Senator Evans’ assessment, will remain to be a central focus of the PHRN moving forward into the 2013-14 financial year.

The other major undertaking of the Council during 2012-13 was to commission an independent review in accordance with the conditions of the PHRN NCRIS Funding Agreement. The review will assist the Council and other stakeholders who are seeking independent advice on progress to date with establishing the national data linkage infrastructure and further development opportunities to assist with strategic positioning in an uncertain funding environment. The Review will cover the period 12 March 2009 to 30 June 2013 and include consideration of the national and international significance of the infrastructure. In February 2013 the Council was able to confirm the appointment of three eminent Australians to the Review Panel: Professor Warwick Anderson AM (CEO, NHMRC) [Chair]; Professor James Best (Head, School of Medicine, University of Melbourne); and Dr Diane Watson (CEO, National Health Performance Authority). On behalf of the Council, we look forward to the findings of the Review which will play a key role in the future advancement and sustainability of the PHRN.

The 2012-13 year ended on a very positive note for the PHRN with the announcement in the Federal Budget in May 2013 of a $186 million allocation for the NCRIS Program. The funds were allocated for a two year period starting 1 July 2013 and an allocation process was immediately commenced by DIICCSRTE. The Council was advised on 1 August 2013 that the PHRN had been allocated $4.915 million from the program known as ‘NCRIS 2013’ and an investment plan for primary distribution of funds to the regional PHRN components was developed by the Program Office in consultation with Council and the Project Participants. On behalf of the Council I would like to congratulate and thank all involved in this process and believe that this decision for the Australian Government to provide significant further funding is testament to the PHRN’s capability in delivering excellent return on investment.

In closing I would like to thank the Management Council, Dr Merran Smith, directors and staff of all Project Participants and our funding partners for their hard work and commitment in developing the PHRN’s data linkage infrastructure. I look forward to watching the PHRN facilitate “big science” in population health, stronger evidence based health policies and superior national health outcomes into the future.

Professor Brendon Kearney AM
REPORT FROM THE PHRN CHIEF EXECUTIVE

Much of the work funded through PHRN NCRIS is now complete with five Project Participants reporting activities against PHRN NCRIS milestones during 2012-13. These Project Participants were the Centre for Data Linkage (CDL), the Sax Institute, Victorian Data Linkages (VDL), the PHRN Program Office and the Queensland node. Funding for PHRN will continue until 2015 to enhance and operate Australia’s population health data linkage and access infrastructure through the Education Investment Fund Super Science Initiative (EIF-SSI), the Collaborative Research Infrastructure Strategy (CRIS) and the NCRIS 2013 program. The Program Office continued to manage the remaining PHRN NCRIS and EIF-SSI contract commitments during the year as well as the new CRIS and NCRIS 2013 allocation and reporting process. With tight timeframes and a demanding reporting schedule, I would like to thank the PHRN Contracts Manager Ingrid Landwehr, all Project Participants, UWA and staff at DIICCSRTE for their hard work, commitment and patience throughout the year.

Good progress with data linkage infrastructure was made by all PHRN Project Participants during the year. The Program Office has made significant progress with development of national elements of the infrastructure including online applications and the metadata resource. The system testing collaboration and the CSIRO/ABS/Sax collaboration on confidentialisation of research outputs have also progressed well. The CDL has developed and implemented a number of enhancements to the national linkage system and continued work into development of the national Data Delivery System (DDS). The SURE remote access laboratory has expanded capacity and coverage to become a national facility for appropriately accredited researchers. At the Australian Institute of Health and Welfare (AIHW) the development of a fully operational secure data integration capability and design of collaboration mechanisms across PHRN to enable researchers to access Commonwealth data were completed.

Evolution and enhancement of the regional data linkage units has also continued successfully. The NSW Centre for Health Record Linkage (CHeReL) and WA Data Linkage Branch Custodian Administered Research Extracts Server (WADLB CARES) infrastructure developments are making data delivery more efficient and effective by providing tools to assist data custodians. At VDL the Better Patient Data project has made considerable progress and implementation of a new data linkage platform is underway. Tasmania Data Linkage Unit (TDLU) is now in a position to accept and process applications for linked data while SANT DataLink has made good progress with linking NT Births and Deaths data back to 1868 and 1870 respectively. Despite delays in finalising several Queensland Annual Business Plans, good headway has now been made and a highlight for the year was the formal opening of the Research Linkage Group held at the University of Queensland in May 2013.

2012-13 saw significant progress with the PHRN Proof of Concept collaboration initiatives designed to test, refine and showcase the national linkage infrastructure. Analysis for the first Proof of Concept collaboration (POC#1) on hospital related mortality has continued and linkage of QLD and SA data to NSW and WA data has been completed by the CDL to facilitate completion of epidemiological outcomes for POC#1. A Final Report based on the preliminary analysis of WA and NSW data was submitted to the WA Department of Premier and Cabinet in June 2013 and accepted in July 2013. A contract has been executed with the University of NSW to undertake the second PHRN Proof of Concept collaboration (POC#2) looking at burden of injury in the Australian
population and significant progress has been made in obtaining custodial and ethics approvals for this project. The third Proof of Concept collaboration (POC#3) involving linkage of health and education data has commenced and protocols are being finalised with the researchers. Excellent progress in custodian and ethics committee approvals has also been made for the final Proof of Concept Collaboration (POC#4) which will seek to link national vaccination data with midwives, hospital, infectious disease and mortality data from WA and NSW via the AIHW’s accredited Integrating Authority to look at burden of vaccine-preventable disease in children.

Recognising the importance of effective infrastructure to support research data management, DIICCSRTE established a Research Data Infrastructure Committee in mid-2012 of which I was asked to become a member. The Committee’s remit was to undertake an analysis of the current national research data landscape, to form the basis of advice to the Australian Government regarding how to optimise existing and future investments in research data infrastructure. To date the Committee has held four meetings which have provided an excellent opportunity for me to network on behalf of the PHRN with the Australian research infrastructure community and advocate for the continued support of the PHRN’s operations within the scope of future funding frameworks.

In what has been an exciting and extremely busy year for the PHRN, the staff and management of all Project Participants have shown great commitment and support of the network and have accordingly responded to the various challenges presented throughout 2012-13 with efficiency and professionalism. The spirit of collaboration within the PHRN has been evident on many occasions where knowledge, expertise and experience has been shared amongst the units. This has resulted in the development of advanced technical systems, research support services and robust governance structures throughout the jurisdictions.

I would like to acknowledge the support and advocacy of our primary funding partner, DIICCSRTE, and all state and territory co-funders and I look forward to continuing these relationships into the future. As the maturation of the units continue and core linkages and systems are expanded, the demand for linked data services by the research community will continue to increase. I am confident that the capacity of the PHRN’s infrastructure will support this demand and more valuable research outcomes will be generated resulting in enhanced health and well-being of the community.

Dr Merran Smith
CREATING A SUSTAINABLE FUTURE

PHRN NCRIS FUNDING EXTENSION AND DEEDS OF VARIATIONS

Following the Program Office’s completion of a budget review related to unspent PHRN NCRIS funds, some residual PHRN NCRIS funded activities will continue in 2013-14. A Deed of Variation to the PHRN NCRIS Funding Agreement which was executed on 1 May 2013 to cover these activities extended the project completion date to 30 June 2014 for the Program Office, CDL, the Sax Institute, VDL and Queensland. The Variation included provision for unallocated DDS funds to be allocated to the CDL ($180,000) to lead the development of DDS Phase 3 and to the Sax Institute ($681,000) to supplement EIF-SSI funds for expanding the NSW/ACT SURE into a national facility. Variations to PHRN NCRIS Participant Agreements have been prepared to cover these changes.

PHRN EIF-SSI FUNDING EXTENSION AND DEEDS OF VARIATIONS

With advice from DIICCSRTE that PHRN EIF-SSI funded activities may continue until 31 December 2014, a number of Project Participants have extended their EIF-SSI activities into 2013-14 in order to complete their milestones. A deed of variation to the Participant Agreement between UWA and each Project Participant has been executed for the Telethon institute for Child Health Research (TICHR), AIHW, Curtin University, Sax Institute and the University of South Australia while deeds of variation for NSW and Tasmania are in the process of execution. Participant Agreements are yet to be executed for Victoria and WA.

PHRN COLLABORATIVE RESEARCH INFRASTRUCTURE SCHEME (CRIS) FUNDING

The CRIS is an interim funding solution to allow priority research infrastructure projects funded under NCRIS and/or the Super Science Initiative to remain operational. Following a competitive selection process, the PHRN was advised in late 2012 that it had been allocated $3.085m from a total $60m CRIS budget. Strict guidelines around the CRIS funds mandated that the investment must not be used for the acquisition or development of new infrastructure, or to expand the capacity of existing infrastructure – rather it is intended to support the operation of existing infrastructure including management and governance costs at both the node and national governance levels. In addition, CRIS funding only operates to support chosen facilities after NCRIS and EIF-SSI investment is expended.

The Chair of the Management Council led the collaborative development of a funding proposal which outlined a plan for CRIS investment for the PHRN. Based on the funds available, it was mutually agreed by Council that the CRIS investment be directed towards the national elements of the PHRN to support the following program of work:
• PHRN Program Office – continuation of coordinating governance and management including contract and financial management; policy development and implementation; and some national researcher services and training.

• Australian Institute of Health and Welfare (AIHW) – facilitation of the ongoing operation of the AIHW’s data integration infrastructure, processes and procedures, including maintaining a secure data centre and necessary staffing to comply with its accreditation as a Commonwealth Integrating Authority.

• The Secure Unified Research Environment (SURE) - support of the operations of the PHRN’s only remote-access data laboratory for the analysis of linked health and related data including staffing costs and infrastructure maintenance and hosting.

• The Centre for Data Linkage (CDL) - operation and refinement of the CDL national data linkage infrastructure, continued research and Innovation in data linkage methods, operation of the national Data Delivery System (DDS) and support of linkage of Commonwealth data for research through collaboration between CDL, AIHW and Sax Institute.

The PHRN CRIS Conditions of Grant agreement between UWA (remaining as the lead agent) and DIICCSRTE was executed on 7 March 2013. The PHRN CRIS Implementation Plan was submitted to DIICCSRTE on 3 May 2013 as required. This was approved by DIICCSRTE on 13 May 2013. PHRN CRIS Participant Agreement templates are currently being prepared and it is anticipated that these will be fully executed for all project participants by December 2013. The Program Office and the Sax Institute will commence PHRN CRIS funded activities in the second half of 2013. The two national data linkage services AIHW and CDL will commence in January 2014 consistent with the PHRN CRIS Implementation Plan.

**PHRN NATIONAL COLLABORATIVE RESEARCH INFRASTRUCTURE SCHEME 2013 (NCRIS 2013) FUNDING**

As part of the 2013-14 Budget, the Australian Government announced additional funding for the renewal of NCRIS. The renewed NCRIS will provide $185.9 million from 2013-14 to 2014-15 to secure Australian researchers’ access to current major research facilities and the supporting infrastructure and networks necessary to undertake world-class research. PHRN Chief Executive Dr Merran Smith attended an NCRIS Capabilities Day on Friday 14 June 2013 in Canberra and in early July the PHRN was informed that it will receive $4.915m in NCRIS 2013 funding.

The Program Office supported execution of the PHRN NCRIS 2013 Funding Agreement between DIICCSRTE and UWA which was executed on 2 August 2013. This agreement will provide funding for PHRN components not funded under CRIS and will support the operation and maintenance of existing PHRN infrastructure through to 30 June 2015. NCRIS 2013 Participant Agreements between UWA and Project Participants will be prepared in late 2013. Project Participants in NCRIS 2013 include the Program Office, the AIHW, the CDL, the Sax Institute, the CHeReL, VDL, TDLU, SA NT DataLink and Queensland Health RLG.
PHRN GOVERNANCE: ENHANCEMENT AND PROGRESSION

PHRN MANAGEMENT COUNCIL

The PHRN Management Council continued to meet on a quarterly basis throughout 2012-13. Besides its ongoing responsibilities in overseeing the implementation of the PHRN NCRIS and EIF-SSI Investment Plans, a primary focus of the Council was to develop comprehensive and collaborative proposals for the two new tranches of funding through the CRIS and NCRIS 2013 investments. Tight timeframes surrounding funding announcement and application deadlines meant that the Council members were required to work expeditiously to consult with their respective nodes and stakeholders to develop submissions for consideration for the CRIS and NCRIS 2013 proposals. Due to a finite amount of funding and 12 eligible Project Participants, the Council had to make difficult strategic decisions but the outcomes of this process led to the PHRN successfully obtaining a further $8m of Commonwealth research infrastructure investment. The Council will now continue to oversee the development and implementation of the investment plans for the PHRN CRIS and PHRN NCRIS 2013 funding.

The Management Council continued to have an active role in maintaining relationships with its Commonwealth partners. The Australian Government’s Department of Health and Ageing continued to be represented on the Council to enable bi-directional flow of information between the PHRN and the Department which has been extremely valuable in the context of the PHRN’s activities in the Commonwealth Integrating Authority space. At least one representative from DIICCSRTE has been in attendance at every meeting of the Management Council and this arrangement has also been invaluable, particularly during the announcement of new funding opportunities and the preparation of applications to secure a share of this funding for the PHRN.

During 2012-13 a number of the Management Council’s subcommittees met on a regular basis to provide advice on policy and other related matters. The PHRN Ethics, Privacy and Consumer Engagement Advisory Group has considered a number of issues including the refinement and roll-out of the PHRN’s training for Human Research Ethics Committees (HRECs), provision of data linkage information to patients/subjects at point of collection, consumer engagement through community conversations and the review of the PHRN’s Consumer and Community Participation, Privacy and Scientific and Ethical Review policies. The PHRN Operations Committee continued to provide a forum for discussion on technical linkage matters and also served as a reference group for the ongoing development of the PHRN’s Data Delivery System being developed and implemented by the CDL.

The PHRN Program Office has continued as secretariat for the PHRN Management Council and its advisory groups (excluding the Operations Committee) under PHRN NCRIS and EIF-SSI. This role will be maintained throughout the implementation of the PHRN CRIS and NCRIS 2013 investment plans.
In mid-2012 the Management Council commissioned an independent review of the PHRN in accordance with a requirement in the PHRN NCRIS Funding Agreement for a program review. The purpose of the Review is to provide funders and other stakeholders with an independent assessment of progress to date by PHRN in establishing Australia’s national data linkage infrastructure for research to inform policy, planning and management to improve the health and wellbeing of all Australians. The Review will address the Network’s key achievements, challenges and future opportunities. This will assist PHRN and its supporting agencies and institutions with strategic positioning for further infrastructure development.

The Review will cover the period 12 March 2009 to 30 June 2013. Following a call for nominations from the Council, a Review Panel has been appointed. Professor Warwick Anderson AM (CEO, NHMRC) has agreed to chair the Review and Professor James Best (Head, School of Medicine, University of Melbourne) and Dr Diane Watson (CEO, National Health Performance Authority) have agreed to be Panel Members. An external consultant has been retained to provide executive support to the Panel members. A Project Support Group comprising the Chair of the PHRN Management Council and the Chairs of its sub-committees has been convened to provide information and feedback on background information to the Panel members, to resolve any issues that arise where appropriate and to assist Council in the implementation of any recommendations made as a result of the Review.

The Review Panel will complete the following activities and make recommendations as appropriate:

1. Assess the extent to which the PHRN and its Participants have achieved the Network’s aims and objectives.
2. Note the Network and Participant certified statements of income and expenditure to 30 June 2013 (where available). Comment on the extent to which expenditure represents value for money relative to the infrastructure and related processes that have been developed.
3. Review the extent to which the new infrastructure has met or will meet the needs of researchers and policy makers for access to linked population level data within and between jurisdictions and sectors.
4. Consider the significance of the PHRN infrastructure in the national and international context.
5. Consider the role of the PHRN in the future development of a distributed national data linkage infrastructure in Australia. Issues to be considered include:
   - Any changes in structures and processes to assist PHRN Participants to achieve the aims and objectives of current plans and agreements;
   - Options for further development and maintenance of PHRN and related data linkage infrastructure in the next 5 years, including potential future funding sources; and
   - The role of the PHRN in the development of Australia’s data linkage infrastructure in the next 5 years.
The Review will take place over the second half of 2013 and will involve a call for written submissions as well as a number of face-to-face public hearings. It is expected that the findings of the Review will be available in early 2014.

PHRN INFORMATION GOVERNANCE FRAMEWORK

Work continued on the development and refinement of the PHRN Information Governance Framework that was commenced in the previous financial year. Under the guidance of CQR Consulting and a Project Control Group containing representation of all of the Project Participants, a final draft of the Framework was completed in late October 2011. This was endorsed in principle by the Management Council at its November 2011 meeting. The Framework outlines a set of controls and procedures to ensure that privacy and confidentiality of data is maintained throughout all PHRN activities and now forms a critical part of the PHRN’s mitigation strategy to address possible privacy and security breaches.

Following dissemination of the endorsed PHRN Information Governance Framework throughout the network, all Project Participants have now developed strategies to address identified risks. These include security manuals, security awareness checklists, information security guidelines, confidentiality deeds for staff and researchers, security protocols and incident and breaches investigation processes. In addition, with the encouragement of the Commonwealth Department of Health and Ageing (DOHA), the Framework was provided to the Chair of the National Health Information and Performance Principal Committee (NHIPPC) for consideration in June 2012.
DATA LINKAGE CAPABILITIES AND OPERATIONS: EXPANSION AND TESTING

2012-13 was a busy year for all Project Participants which included amongst other things contract and data transfer negotiations, development, refinement and operation of infrastructure, meeting rigorous reporting requirements and managing submissions for the new CRIS and NCRIS 2013 investments.

NATIONAL UNITS

CENTRE FOR DATA LINKAGE (CDL)

Under PHRN EIF-SSI, the CDL committed to expand the development of National Infrastructure to increase the technical capability and know-how to manage and transform datasets as linkage demand, complexity and size grows. In 2012-13 a technical review of the CDL's production linkage system to identify gaps and/or limitations in existing components and to prioritize future system development and enhancements was completed. The review considered performance and functional aspects of the system. On the basis of this review, a system re-development and enhancement plan was prepared. Following on from the review, a number of system enhancements were identified. These are being developed and implemented using the business development processes established during NCRIS.

Linkage quality has also been assessed during this process to ensure that the production system either maintains or improves upon the quality benchmarks from the Proof of Concept linkage runs. As part of this assessment, the CDL also investigated the effect that data cleaning and standardisation have on linkage quality. The results of the research have been published. [Refer: Randall, Ferrante, Boyd and Semmens (2013), The effect of data cleaning on record linkage quality. BMC Medical Informatics and Decision Making 2013, 13:64. http://www.biomedcentral.com/1472-6947/13/64.]

The CDL has now established a University-based Steering Committee to oversee EIF SSI developments. The CDL Steering Committee was set up to have responsibility for 1) the development and implementation of the CDL strategic plan; 2) ensuring the reporting of activity to DIISRTE through the PHRN Management Council; and 3) providing advice, guidance and support for the CDL on project issues.

Other areas of activity for the CDL included undertaking the second phase of the PHRN’s Data Delivery System and completion of cross-jurisdictional linkage for the first PHRN Proof of Concept Collaboration. These are discussed in more detail below.
SECURE UNIFIED RESEARCH ENVIRONMENT (SURE)

Substantial progress has been made on development of the SURE facility to accommodate researchers nationally, most notably, the national launch of the SURE facility in Sydney in July 2013. The second stage of hardware implementation for SURE at its first site at the Global Switch data centre in Sydney was completed between April and July 2012. Formal agreements for the use of SURE have been executed with a number of data custodian agencies including the AIHW, the NSW Ministry of Health and the Cancer Institute NSW.

Uptake of the SURE facility has continued to increase at a steady state throughout 2013, following the introduction of user charges in 1 January 2013. As at 30 June 2013, the facility had 40 users and 13 project workspaces established.

The policy framework and user support functions of the SURE team were further developed in 2013 with key activities including:

- Two SURE researcher training workshops were held and content for an online version of the training was developed and piloted; and

  Development and refinement of a range of instructional guides including website content for new users of the SURE facility.

The infrastructure of the SURE facility will further expand in the 2013-14 financial year, involving the establishment of a second site. Planning for this next phase of development has commenced. At this stage, it is anticipated that that SURE’s second site will be co-located with the NSW node of the Research Data Storage Infrastructure (RDSI), operated by Intersect Australia. This co-location is highly desirable for the future sustainability of the SURE facility. Funding under CRIS in conjunction with income earned through SURE access fees, will support the operations of the SURE facility up to December 2014.

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (AIHW)

Following formal accreditation of its Data Integration Services Centre (DISC) in June 2012, the AIHW has continued to engage with the Commonwealth Department of Health and Ageing (DoHA) to establish arrangements for researcher projects for which it will be the Integrating Authority. This continued engagement has resulted in interim arrangements for release of DoHA data for a number of data integration projects. The AIHW is continuing to refine processes and a draft “Project Application and Approval Support Process” has now been developed. The AIHW, DoHA and the Commonwealth Department of Human Services are testing these processes on a number of active and prospective projects to develop a sustainable and effective model for the long term. These processes will replace the existing processes, resulting in a streamlined process for Integrating Authorities, data custodians and researchers.

The DISC Data Laboratory now provides a secure access environment for researchers to perform analysis on de-identified and appropriately confidentialised datasets. Researchers can access the datasets provided and use familiar analytical packages but they cannot remove output of analysis.
Agreements are now in place between the AIHW and the CDL and between AIHW and Sax Institute. The agreement with CDL provides for AIHW to subcontract data linkage work to the CDL, providing that data custodians are comfortable with this. Any projects undertaken under such a subcontracting arrangement will confer the provisions of the AIHW Act on CDL personnel involved in the project. The agreement with Sax enables dissemination of data through SURE.

REGIONAL UNITS

SOUTH AUSTRALIA/NORTHERN TERRITORY

SA NT Datalink has continued development of the South Australian and the Northern Territory data linkage capability, including work to make the linkage operation financially self-sustaining. In 2012-13 nine projects were approved with data released for three research studies including the South Australian data required for the PHRN Proof of Concept Number 1 Inpatient Safety and Quality, the Pilot release for the NT Enhanced Reporting on Closing the Gap Targets, and the SA Health Performance Council’s Palliative Care study.

There has been significant progress in the past 12 months on the Enhanced Reporting on the ‘Closing the Gap Targets’ project, particularly with the release and linking of the NT Births and Deaths data back to 1868 and 1870 respectively. This project has allowed the Births and Deaths data to be linked with NT Department of Health’s ‘Client Master Index’ which is a unique identifier for individuals using NT Department of Health services from 1991. This research infrastructure now resides within an especially prepared secure area for storing the de-identified data. Agreements have also been made with the NT Registrar for Births, Deaths and Marriages on how this research infrastructure would be used to release de-identified Birth and Death Data.

SA NT DataLink has now negotiated approvals to link records from 33 government-held administrative datasets, building them into the Master Linkage File. This file currently contains information to link 1.6 million South Australians and 175,000 Northern Territory residents.

A successful Community and Consumer Conversation Event was held with a ‘Cancer’ theme in Adelaide in November 2012. This event was run in partnership with the Health Consumer Alliance of South Australia and the SA NT DataLink Consumer Reference Group, and attracted over 60 community members and consumer participants, with the majority being individual health consumers who had never heard of data linkage.

The Foundation Director of SA NT Datalink, Professor Robyn McDermott, resigned her position to take up a new post at James Cook University in Cairns. Mr Andrew Stanley, who has served as Chair of the SA NT Datalink Steering Committee and as the SA/NT representative member on the PHRN Management Council, has been appointed as Professor McDermott’s replacement.
VICTORIA

In 2012-13 Victorian Data Linkages (VDL) has continued to create and maintain additional linkages within and between core population health and health services data collection. VDL continued to operate with limited staff resources in 2012-13 due to a state-wide staffing freeze initiated through the Victorian Sustainability in Government initiative. However it continues to provide researchers with effective and reliable clinical and population health research data linkage facilities and services. This has included providing data linkage services to over 60 research programs at state and national levels. VDL has increased the Victorian Linkage Map (VLM) to 10 datasets linked and routinely updated. VDL continues to improve the existing quality of the enduring data linkage for the hospital datasets.

The new secure data linkage platform and software for the VDL have been purchased and implementation is scheduled to be finalised by September 2013. As part of this process the Health Design and Authority team from the Office of the Chief Information Officer was engaged to plan, develop and implement solution architecture for the project’s operational processes, ongoing maintenance and its interfaces. In addition, VDL engaged the Victorian Department of Health’s Information Security Manager to assess and provide guidance on the Department’s security and technology architecture standards for the whole project.

TASMANIA

An off-the-shelf data-linkage engine was purchased by the Tasmanian Data Linkage Unit (TDLU) in the second half of 2012. This is now supported through a series of database scripts that enables data, upon receipt from custodians, to be processed in a timely manner. All actions necessary to respond to user requests for linked data and undertake all technical functions associated with the linkage itself are now complete. TDLU is now in a position to receive and process applications for linked data.

TDLU is now planning for the supply of core datasets from the Department of Health and Human Services under the terms of the Data Exchange Agreement developed with that organisation. The data linkage unit has now also negotiated with the Department of Education, Employment and Workplace Relations (DEEWR) for the supply of Australian Early Development Index (AEDI) data for linkage, enabling linkage of health and education data to increase research opportunities using linked health and education data. The first application of the AEDI by the TDLU will be in the PHRN’s third Proof of Concept #3 Collaboration.

QUEENSLAND

HealthLinQ hosted the formal opening of the Regional Linkage Group (RLG) within Queensland Health (QH) at the University of Queensland on 1 May 2013. This launch signified the recruitment of the RLG’s full complement of 10 staff, allowing them to operate at full capacity. This has not only allowed for production linkage to commence, but has also reduced the time for the delivery of project-specific linked data to researchers.
Over the last year, ChoiceMaker was fully installed and models were developed for use on QLD data. Production linkage went live in May 2013 and by 30 June 2013, two years’ of data had been linked with the new system. Data currently being linked with the new system include internal linkage of episodes within admitted patient data, and linkage of admitted patient data to death registration data, birth registration data and perinatal mothers data. Linked data are currently available from 1 July 2003 to 30 June 2011. It is anticipated that an additional 5 years’ of data will be linked by the end of the 2013 calendar year. In addition, a further three data collections will be added to the seven years of linked data during this period.

Health LinQ has facilitated the access to datasets linked by the RLG for over twenty research groups during 2012-13. This has included presenting information on linkable datasets, assisting with ethics and Public Health Act (PHA) applications and providing methodological advice on the use of linked data. Maintenance of the HealthLinQ website has continued throughout the year as this continues to be an important resource for both promotion of the QLD node and national PHRN network, and as a tool to distribute information to researchers.

A comprehensive review of the QLD node was undertaken by an external consultant and the key recommendations are being implemented. Delays in the contracting process with the Queensland State Government (DEEDI) affected the transfer of PHRN NCRIS cash income to HealthLinQ and the project partners and delayed the delivery of some project milestones. These obstacles have now been overcome, and the project period has been extended to allow funds to be spent. Delays were also encountered due to staff cuts and a recruitment freeze at QH that prevented recruitment of staff to fill linkage roles. However, as at 30 June 2013, all positions created for linkage were filled and approval was obtained from the Director-General and internal Employment Management Process team to extend the positions until 30 June 2014.

WESTERN AUSTRALIA

The WA Data Linkage Branch (WADLB) has continued to work toward completion of the CARES design, testing and plan for seamless migration of data and processing. CARES will create and maintain a suite of standardised, validated and de-identified data extracts and forward these to researchers on behalf of data custodians. The CARES system has now been procured and work is underway to develop a fully functioning production extraction service. The project team are currently working closely with various data custodians to test the CARES infrastructure.

NEW SOUTH WALES/AUSTRALIAN CAPITAL TERRITORY

PHRN EIF-SSI funds have been allocated to the NSW/ACT node of the PHRN to fund development of infrastructure to enable more timely and efficient access to health and health related data in these states. Specifically, this will be achieved through addressing significant bottlenecks by automation of NSW hospitalisation data feeds, synchronisation of data custodian and linkage unit handling of hospitalisation data, and optimisation of linkage and data management systems. This requires new or upgraded applications at two sites: the NSW Ministry of Health and the Centre for Health Record Linkage (CHeReL), Cancer Institute NSW.
The NSW Ministry of Health has developed software that automates the handling of NSW hospitalisation records and will reduce the lag-time in their availability by 75%. The software is being deployed into production in a series of releases as new functionality become available.

The CHeReL has deployed a new version of software which provides a more efficient and sustainable solution for managing the increasingly large and diverse linkage files required by the government and research sector. The first phase of development and testing was completed in May 2013 and the new version of software was deployed to production in June 2013.
NATIONAL STRATEGIES AND INTERNATIONAL COLLABORATIONS

PROOF OF CONCEPT COLLABORATIONS

PROOF OF CONCEPT #1

The first Proof of Concept Collaboration (POC#1) which is using linked data to examine hospital related mortality has continued successfully in 2012-13. The CDL completed linkages of WA and NSW data for POC#1. The preliminary analysis on WA and NSW data was completed during the year with relatively low cross border flows between the two states. The Final Report for POC#1 based on analysis of the WA and NSW data was submitted to the WA Department of Premier and Cabinet on 2 July 2013 and accepted on 11 July 2013.

The original completion date for POC#1 was further extended to allow time to include Queensland and SA data in the study. The addition of Queensland and SA data to POC#1 will allow more meaningful statistical analysis to be carried out. Long delays in formal data custodian approval to release data and protracted negotiations in data exchange agreements were experienced. The data transfer agreement between Curtin University and the Queensland Department of Health was executed in September 2012. The data transfer agreement between Curtin University and the SA Department of Health was executed in October 2012. Despite these delays, it is anticipated that future requests for data from these states will be streamlined now that a precedent is in place and analysis of data from the four states is expected to be completed by December 2013.

PROOF OF CONCEPT #2

POC#2 on the burden of injury on hospital morbidity and mortality which plans to link data from WA, NSW, SA, Victoria, Tasmania and Queensland is progressing steadily. The overall objective is to describe and compare health care utilisation and mortality in injured and non-injured populations in Australia. A Financial Assistance Agreement between TICHR and the Department of Commerce WA for POC#2 funding was executed in October 2012. A Funding Agreement between TICHR and the University of New South Wales was executed in April 2013 to engage UNSW to conduct POC#2. Significant progress has been made in seeking data custodian and ethics approvals for POC#2.

PROOF OF CONCEPT #3

POC#3 on early childhood development will link data from WA, NSW, SA, Northern Territory and Tasmania with data from the national Australian Early Development Index which is held by the Commonwealth Department of Education, Employment and Workplace Relations. The aim of POC#3 is to explore the relationship between perinatal factors and developmental and educational outcomes in early school-aged children. Progress was made with the protocol for POC#3 but work is continuing to resolve outstanding issues.
PROOF OF CONCEPT #4

The fourth Proof of Concept Collaboration (POC#4) which is supported through the system testing component of the PHRN EIF-SSI funding was endorsed by the Management Council at its August 2012 meeting. The proposal is for linkage of the Australian Childhood Immunisation Register (ACIR) to state based health data to evaluate and inform Australia’s immunisation program. POC#4 will involve the linkage of state-territory and Commonwealth data to be conducted by the AIHW as an Integrating Authority and data linkage unit.

The chief investigators of the project met in Perth in August 2012 to develop the project methodology. The approval process for POC#4 has taken longer than anticipated due to a number of challenges, the main challenge relating to the approval process for the release of the ACIR data as to date has been no established formal application process for this collection. Ongoing dialogue between the investigators, data custodians and ethics committees was extremely valuable in refining the study protocol which has enabled formal submission of applications to the relevant authorities. All six HREC approvals required for the conduct of the study have now been obtained as well as data custodian approvals from all state data custodians. Preparation of the Public Interest Certificate for the release of ACIR data is underway.

An Aboriginal Immunisation Reference Group has been established to provide Aboriginal community perspectives on the Aboriginal component of the research and the researchers believe this reference group will provide a valuable contribution to the study and beyond. In addition, a process for undertaking the disclosure risk assessment by AIHW and subsequent release of data to the researchers has been agreed to by all stakeholders. The researchers are optimistic that data will be available by the end of this year if there are no delays with the release of ACIR data and the disclosure risk assessment process.

PROOF OF CONCEPT SUPPORT

The Department of Health WA provided Proof of Concept coordination service in conjunction with PHRN Program Office staff in 2012-13. This important role included supporting meetings of the PHRN Proof of Concept Reference Group and overseeing development and reporting of the four POC collaborations. Ms Diana Rosman notified members of her intention to step down as Chair of the POC Reference Group on 30 June 2013. Management Council supported the appointment of Ms Teresa Dickinson from the AIHW as Chair of the PoC Reference Group. Research Assistant Professor Anna Kemp has been appointed as the new researcher member of the Reference Group to replace Prof Steve Kisely. A Proof of Concept Coordinator has been appointed by the Program Office to continue the work in 2013-14. This appointment is due to commence in August 2013.

DATA DELIVERY SYSTEM

The PHRN Data Delivery System (DDS) is an ensemble of technology and standards, agreed operational procedures, software and supporting IT infrastructure that will provide harmonised national mechanisms for secure and efficient transfer of data between nodes of the PHRN and from data custodians to linkage units and researchers for approved projects.
Phase 1 activities (DDS1) comprised an evaluation of selected technologies for secure data transfer and the defining of simple but sufficient metadata and data file formats for data being exchanged between PHRN parties. This was completed in 2011-12. Phase 2 (DDS2) was endorsed by the Management Council in 2012 and activities were undertaken by the CDL in 2012-13. DDS2 delivered a service which provides the PHRN with the ability to transfer data securely and efficiently between stakeholders for the purpose of conducting PHRN projects.

The solution finally proposed was Accellion. It is widely adopted across the public and private sectors, is highly configurable and flexible, and built with the ability to comply with industry standards (including security). Accellion is a web-based solution which enables users to quickly, easily and securely send files/folders up to 100GB to internal and external recipients with enterprise data security and compliance. The solution offers comprehensive file tracking and reporting required to meet industry and government regulations.

The key outcomes for DDS2 were:

1. A secure data delivery system that meets the requirements of PHRN projects;
2. A user friendly, efficient and trusted mechanism for transferring data between project participants;
3. A system that adheres to PHRN Policies, Principles and Standards (e.g. PHRN Information Governance Framework);
4. A low support and maintenance overhead; and
5. A system that is scalable to meet the current and future needs of the PHRN.

The CDL is also responsible for DDS Phase 3 integration activities (DDS3), leveraging off work done in Phase 2. DDS3 activities will be undertaken in 2013-14 and will focus on integration of new national and jurisdictional data linkage technology developments with the DDS, establishment of business processes, documentation (e.g. access agreements) and administrative support for a DDS, and the development of plans to support broad deployment (including support, integration tools).

**NATIONAL SURE FACILITY**

DDS funding was also reallocated to the Sax Institute ($681,000) to supplement EIF-SSI funds for expanding the NSW/ACT SURE into a national facility. The facility which is managed by the Sax Institute in Sydney transitioned from an infrastructure development project to an operational facility in 2012-13. SURE was officially launched by Senator Matt Thistlethwaite on 5 July 2012 and is now accepting registrations from the population health research community around Australia to establish a virtual workspace for the secure analysis and storages of linked data.

The policy framework and user support functions of the SURE team were further developed in the 2012-13 financial year with key activities including:

- Executed agreements with data providers for the use of materials in SURE;
- Further development of content on the SURE website to include information on registration, access charges and training;
• Finalisation of an initial pricing schedule for SURE access and implementation of access charges for SURE from 1 January 2013; and

• Development of a range of instructional guides for new users of the SURE facility.

The infrastructure of the SURE facility will further expand in 2013-14 through establishment of a second site. Planning for this phase of development commenced in 2012-13. At this stage, it is anticipated that that SURE’s second site will be co-located with the NSW node of the Research Data Storage Infrastructure (RDSI), operated by Intersect Australia. This co-location is highly desirable for the future sustainability of the SURE facility.

NATIONAL TRAINING AND EDUCATION STRATEGY

Dr Felicity Flack and A/Prof Judy Allen from the PHRN Program Office successfully delivered PHRN training on Ethics and Data Linkage to Sydney-based HREC members on 2 August 2012. As the Sydney training was oversubscribed a second workshop was held on 8 November 2012 in conjunction with training for AIHW, the Federal Department of Health and Ageing (DoHA) and ACT Health HREC members which took place on 12 November in Canberra. Eighteen members of the Tasmanian Health and Social Sciences HRECs attended training conducted in Hobart 12 April 2013. The HREC training will also be held at the Australian Ethics Network Conference in November 2013.

As a direct result of the delivery of training for HRECs, the PHRN was approached to assist in the organisation and facilitation of a meeting of the Chairs of the main HRECs around the country which review applications for the use of linked data held in Canberra on 9 November 2012. The meeting offered a forum for the Chairs to contribute to discussion on a range of issues including:

• Minimising the duplication of ethical review;

• Low and negligible risk research;

• Program of work applications;

• Linkage of biological/clinical testing/biobanking data;

• National ethics application form; and

• HREC training.

An essential part of the national PHRN training program is the evaluation of the effectiveness of the training to its target audience to enable continual improvement. Pre- and post-training evaluation forms were distributed on site at each of the HREC training sites and revealed the majority of participants considered that they achieved an improvement in their knowledge, attitudes and skills after completion of the course.

Research has also shown that program effects differ for those programs that are evaluated pre and post training when compared with those who also evaluate longitudinally (Antes et al., 2009). The PHRN National Training Coordinator therefore considered it important to conduct a third evaluation, once participants had had the opportunity to apply their knowledge and skills in
reviewing applications to use linked data. This would enable the PHRN to determine whether the post training results are sustainable over a period of time and if the knowledge and skills obtained from the training can be translated to practice. As such, a follow up study has been developed that will obtain participants perspectives on whether any improvements had taken place in relation to their confidence and ability to review data linkage ethics applications as a result of the training. HREC approval has been sought by the Sir Charles Gairdner Hospital Research Ethics Committee to undertake the study. It is expected that this work will be completed in the second half of 2013.

NATIONAL CLIENT SERVICES CONSULTATIONS

The PHRN Program Office’s consultation process with over one hundred researchers who are current and future users of linked data concluded in August 2012. The three main perceived challenges associated with undertaking research using linked data in Australia were found to be 1) lack of information; 2) complexity of application and approvals processes; and 3) data custodian resourcing to support research. A paper summarising the key findings of this process was presented to the Management Council in October 2012 for consideration. The paper also included results of a national scope of current and planned client services offered by the PHRN Project Participants conducted in the previous financial year by the Program Office.

All researchers who participated in the PHRN researcher consultations were supportive of a streamlined approach to the access and delivery of linkable data, including the development of an online application and tracking system and a generic application form for cross-jurisdictional linked data projects that will be accepted by all PHRN data linkage units. As a result, the Program Office contracted the Birchman Group in early June 2013 to develop a business concept document which will seek to identify the requirements for a PHRN Online Application System. The business concept paper will be informed by the findings from the client service, researcher and metadata consultations conducted by the Program Office.

In conjunction with the researcher consultations, the Program Office undertook a scoping exercise to determine current/planned metadata tools and practices utilised by all PHRN project participants as part of the Metadata project. The Program Office also conducted an environmental scan of available tools, software and standards for the management of metadata. Based on the findings of the consultations with researcher, PHRN Project Participants and the environmental scan, a draft PHRN Metadata Guidelines document was developed. The purpose of the PHRN Metadata Guidelines document is to provide guidance for project participants to establish efficient practices in order to provide consistent, data user orientated and accurate metadata available within the PHRN infrastructure. The Guidelines have now been circulated to PHRN Project Participants and other key stakeholders for feedback.

CSIRO/ABS/SAX COLLABORATION ON DATA CONFIDENTIALISATION

The CSIRO has undertaken a project to review confidentiality issues associated with analysis outputs generated in a secure analysis laboratory such as SURE, and then to examine different approaches to confidentialisation of these outputs for publication. Here confidentialisation of an output refers to the application of treatments such as suppression, aggregation or other
modification for the purposes of assuring confidentiality protection.

The funding agreement between TICHR and CSIRO for the collaboration was executed in August 2012. The project, led by Dr Christine O’Keefe, proceeded in four stages and included two workshops. A summary of the key activities of the project is as follows:

- Identify potential points to introduce disclosure risk assessment and confidentialisation processes in the SURE environment, with an initial consideration of potential impacts on research efficiency;
- Identify requirements in the form of statements about privacy and confidentiality in major legislation and regulation applicable in the context of SURE;
- Understand researchers’ and data custodians’ perspectives on disclosure risk assessment and confidentialisation of research outputs, including concerns and constraints;
- Understand and characterise by means of a review of a sample of published research papers and statistical reports,
  - The range and nature of research analysis outputs that researchers may wish to remove from SURE during or after a research project, and
  - The nature, extent and frequency of disclosure risks relating to outputs of research using linked health data, by review of a sample of published research papers and statistical reports;
- Summarise requirements for approaches to disclosure risk assessment and confidentialisation of such outputs;
- Conduct a review of options for approaches to disclosure risk assessment and confidentialisation of data outputs that researchers may wish to remove from SURE during or after a research project;
- Conduct a review of guidance (including guidelines and checklists) that can be provided to researchers to allow them to assess and mitigate disclosure risk; and
  Conduct a review of available software tools and/or development projects.

A draft Final Report of the project containing a summary of the findings of the whole project, together with recommendations for policies, procedures, guidelines, methods and tools for assessing disclosure risks and confidentialisation of outputs, has now been completed and will be made available to PHRN stakeholders in due course.

**CONFERENCE PRESENTATIONS AND WORKSHOPS**

The PHRN was promoted through conferences, presentations, publications, websites, forums, seminars and workshops by the various Project Participants and Council Members throughout 2012-13.
The Chair of the PHRN Management Council represented PHRN at the invitation-only meeting of the Wennberg International Collaboration (WIC) in London in September 2012. Professor Kearney was able to provide an update on the activities of the PHRN and presented the preliminary findings of the first Proof of Concept Collaboration looking at hospital-related morbidity and mortality which was of particular interest to attendees.

Dr Merran Smith, PHRN Chief Executive, gave an invited presentation to the Royal Australasian College of Physicians Annual Scientific Meeting held in Perth on 28 May 2013. Her paper was entitled ‘Data linkage and clinical research: A powerful combination’.

Dr Felicity Flack from the Program Office presented to a meeting of community members interested in becoming health consumer representatives in October 2012 in Perth. Her presentation provided an overview of what data linkage is, which data collections are used and the benefits of using this methodology in population research.

Dr Flack was also invited to present at the National workshop on stroke performance data, care quality and telemedicine held on 10 April 2013. Her presentation was in the workshop session entitled ‘Overcoming the technical and governance issues related to data linkage between external and hospital data sets’.

The third annual PHRN Technical Forum was organized by the CDL team and hosted by VDL on 17-18 October 2012 in Melbourne. Forum presentations included updates on the DDS Phase 2 (CDL), Researcher Consultation (Program Office), specialized linkage methodology (AIHW) and CARES (WADLB); System demonstrations of the National Linkage System (CDL) and the Next Generation Linkage System – including Business processes and Technical Architecture (SANT); Geocoding challenges (CDL and Sax Institute) and a Workshop on the researcher feedback process. The Workshop was well-attended by technical and support staff of most Project Participants and received good feedback from attendees.

Staff from the CDL presented in a number of forums throughout the year including a meeting with researchers using linked data at Edith Cowan University. This provided an opportunity for discussion of the development of the NLS and DDS systems.

**INTERNATIONAL COLLABORATIONS AND RELATIONSHIPS**

PHRN regional and national units had active engagement on international research collaborations in 2012-13.

At a national level, the Sax Institute was involved in the Assessing Preventable Hospitalisations Indicators (APHID) study. This involved Australian and NSW agencies and universities as well as the University of Glasgow and a Glasgow based Medical Research Council Unit.

At the regional level, CHeReL was involved with the Medical University of South Carolina and others in a randomised controlled trial of an intervention for illicit drug users. SANT DataLink has had preliminary discussion with Imperial College London and the University of Bern related to Next Generation Linkage Management System. VDL was involved in a collaboration between
the Mental Health Program in the Victorian Department of Health and the University of California looking at the prevention of victimization of people with severe mental illness through the utility of community treatment.

Staff at the CDL attended a number of meetings with UK collaborators in August-September 2012 to discuss the National Linkage System and DDS systems. Meetings were held with the Scottish Health Informatics Program (SHIP) team to discuss and present development on the NLS and DDS systems, data integration stakeholders across Scottish Government and staff of the the Secure Anonymised Information Linkage (SAIL) Databank at Swansea University.

The Program Office has continued to foster international contacts for PHRN and to increase overseas awareness of PHRN with activities throughout the year. Dr Flack has worked on an International Health Data Linkage Network project on the classification of international data linkage centres. PHRN Management Council Chair Professor Brendon Kearney was invited to attend the Wennberg International Collaborative Annual Meeting in London (as noted above). Together with several other NCRIS capabilities the Program Office submitted a successful application to organise a workshop session in the Third EU-AUS Workshop on Research Infrastructure. Dr Smith has been the Chair of the organising committee for the workshop.

RESEARCH OUTPUTS

Over the 2012-13 financial year, the PHRN Project Participants approved 131 new project applications requesting the use of linked data through the PHRN infrastructure. In the same period, 74 projects that obtained all necessary approvals were provided with data for linkage and analysis.

A total of 11 publications were produced over the course of the year from studies using linked data provided through the PHRN infrastructure. These included peer-reviewed publications in scientific journals, published conference abstracts and formal reports available in the public domain. Another peer-reviewed article authored by the CDL team regarding the development of the PHRN national linkage infrastructure was published in 2012-13, and 8 publications citing the PHRN infrastructure arose over the same period. These publications are listed below:


**NB: Research outputs apply to those related to the PHRN NCRIS-funded linkage units only and do not include those outputs associated with WADLB or the CHeReL.**
# FINANCIAL YEAR IN BRIEF

The following table and diagrams provide a summary of PHRN income and expenditure for 2012-13.

**Table 1: PHRN Financial Overview 2012-13**

<table>
<thead>
<tr>
<th></th>
<th>PHRN NCRIS</th>
<th>PHRN EIF SSI</th>
<th>PHRN Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BALANCE AS AT 1 JULY 2012</strong></td>
<td>4,366</td>
<td>493</td>
<td>4,859</td>
</tr>
<tr>
<td><strong>Income:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DIICCSRTE Cash Contribution</td>
<td>2,244</td>
<td>6,182</td>
<td>8,426</td>
</tr>
<tr>
<td>Cash Co-Investments</td>
<td>(855)</td>
<td>929</td>
<td>74</td>
</tr>
<tr>
<td>In-Kind Contributions</td>
<td>648</td>
<td>3,287</td>
<td>3,935</td>
</tr>
<tr>
<td><strong>TOTAL INCOME</strong></td>
<td>2,037</td>
<td>10,398</td>
<td>12,435</td>
</tr>
<tr>
<td><strong>Expenditure:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salaries</td>
<td>1,894</td>
<td>2,308</td>
<td>4,202</td>
</tr>
<tr>
<td>Hardware and software purchases</td>
<td>366</td>
<td>1,321</td>
<td>1,687</td>
</tr>
<tr>
<td>Operating Expenses</td>
<td>621</td>
<td>-</td>
<td>621</td>
</tr>
<tr>
<td>Contractual &amp; General Expenses</td>
<td>-</td>
<td>133</td>
<td>133</td>
</tr>
<tr>
<td>NCRIS expenditure sub-total</td>
<td>2,881</td>
<td>3,762</td>
<td>6,643</td>
</tr>
<tr>
<td>Cash Co-Investments Expenditure</td>
<td>1,327</td>
<td>447</td>
<td>1,774</td>
</tr>
<tr>
<td>In-Kind Expenditure</td>
<td>648</td>
<td>3,287</td>
<td>3,935</td>
</tr>
<tr>
<td><strong>TOTAL EXPENDITURE</strong></td>
<td>4,856</td>
<td>7,496</td>
<td>12,352</td>
</tr>
<tr>
<td><strong>BALANCE AS AT 30 JUNE 2013</strong></td>
<td>1,547</td>
<td>3,395</td>
<td>4,942</td>
</tr>
</tbody>
</table>
Figure 2: Investment by Project Participant and for Proof of Concept Collaborations 2012-13
Figure 3: Investment by Key Activity Area 2012-13.